

ALASKA STATE LEGISLATURE
HOUSE HEALTH AND SOCIAL SERVICES STANDING COMMITTEE

March 3, 2015

3:07 p.m.

MEMBERS PRESENT

Representative Paul Seaton, Chair
Representative Liz Vazquez, Vice Chair
Representative Louise Stutes
Representative David Talerico
Representative Geran Tarr
Representative Adam Wool

MEMBERS ABSENT

Representative Neal Foster

COMMITTEE CALENDAR

PRESENTATION: ALASKA COMMISSION ON AGING

- HEARD

HOUSE BILL NO. 76

"An Act relating to the Governor's Council on Disabilities and Special Education."

- HEARD & HELD

PREVIOUS COMMITTEE ACTION

BILL: HB 76

SHORT TITLE: GOV COUNCIL ON DISABILITIES/SPECIAL ED

SPONSOR(s): REPRESENTATIVE(s) MILLETT

01/23/15	(H)	READ THE FIRST TIME - REFERRALS
01/23/15	(H)	HSS
03/03/15	(H)	HSS AT 3:00 PM CAPITOL 106

WITNESS REGISTER

DENISE DANIELLO, Executive Director
Alaska Commission on Aging
Division of Senior and Disabilities Services
Department of Health and Social Services (DHSS)
Juneau, Alaska

POSITION STATEMENT: Presented a PowerPoint overview by the Alaska Commission on Aging.

NANCY BURKE, Senior Program Officer
Alaska Mental Health Trust Authority
Department of Revenue
Anchorage, Alaska

POSITION STATEMENT: Testified during the presentation by the Alaska Commission on Aging.

GRACE ABBOTT, Staff
Representative Charisse Millett
Alaska State Legislature
Juneau, Alaska

POSITION STATEMENT: Presented HB 76 on behalf of the bill sponsor, Representative Millett.

PATRICK REINHART, Executive Director
Governor's Council on Disabilities and Special Education
Anchorage, Alaska

POSITION STATEMENT: Testified in support of HB 76.

CHRISTIE REINHARDT
Governor's Council on Disabilities and Special Education
Anchorage, Alaska

POSITION STATEMENT: Testified in support of HB 76.

ACTION NARRATIVE

[3:07:08 PM](#)

CHAIR PAUL SEATON called the House Health and Social Services Standing Committee meeting to order at 3:07 p.m. Representatives Seaton, Tarr, Talerico, Vazquez, Stutes, and Wool were present at the call to order.

Presentation: Alaska Commission on Aging

[3:07:27 PM](#)

CHAIR SEATON announced that the first order of business would be a presentation by the Alaska Commission on Aging.

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DENISE DANIELLO, Executive Director, Alaska Commission on Aging, Division of Senior and Disabilities Services, Department of

Health and Social Services (DHSS), directed attention to a PowerPoint titled "Alaska's Roadmap to Address Alzheimer's Disease and Related Dementias (ADRD)," and spoke about slide 2, "Presentation Outline." She stated that ADRD was becoming an important public health challenge as there was an increase in the senior population in Alaska, noting that this roadmap was the culmination of three years of planning efforts.

MS. DANIELLO presented slide 3, "Roadmap Core Team & Agency Affiliations," which listed the names of the agencies and individuals who served on the core team, and who were responsible for the development of the road map. She noted that it had been a collaborative team effort.

MS. DANIELLO moved on to slide 4, "Alaska's Roadmap to Address ADRD," and paraphrased from the mission statement, which read: "To improve public awareness, promote prevention and early detection, increase access to long-term services and supports, improve availability of safe, appropriate housing, and increase caregiver supports for all Alaskans with ADRD." She said that the cost, currently about \$214 billion nationally, was estimated to "skyrocket" to \$1.27 trillion by 2050, as the senior population continued to boom.

MS. DANIELLO addressed slide 5, "What is Alzheimer's Disease and Related Dementias (ADRD)?" She explained that dementia was not a disease, but an umbrella term which described conditions and diseases resulting in the death of brain cells, which lead to loss of memory, loss of thinking ability, and loss of the ability to perform basic activities of daily living. She relayed that Alzheimer's disease, a slow and progressive disease, was the most common of the nine different types of dementia, and was responsible for 60 - 80 percent of dementia. It can affect each person differently. She listed vascular dementia from stroke, frontal temporal dementia, and Lewy Body dementia as other types of dementia. She noted that dementia was the result of changes in the brain due to the development and accumulation of plaques which formed on the outside of neurons. As these changes were responsible for the cut off of the ability by neurons to communicate or take nutrition, the brain cells would die. She said that, as initially the disease started in the inner most area of the brain which was responsible for memory formation, one of the first symptoms was short term memory loss. As the disease progressed and moved into other areas of the brain, there was loss of language, balance, and higher thinking abilities, as well as changes in personality and behavior. She declared that Alzheimer's disease

caused significant hardship for both the person who had it, and for the family. She relayed that advanced stages resulted in a loss of communication, and a need for help with all functions. In the end, the person was not able to swallow or walk, and would eventually die from other causes, often pneumonia, as infection would set in when a person was unable to move around.

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MS. DANIELLO shared slide 6, "Who does Alzheimer's affect?" which explained who most was at risk for developing Alzheimer's disease. She stated that, although it was most common for people over the age of 65, it was not a common characteristic of aging. She pointed out that there were also diagnoses to younger people aged 30 - 64. She said that there was no known cure and no way to slow down its development. She allowed that there was a growing body of research proclaiming that a healthy lifestyle, healthy eating, regular exercise, stress reduction, plenty of sleep, and social engagement, could delay the onset of symptoms.

MS. DANIELLO pointed to slide 7, "Projected Alaska Senior Population 2014 - 2042," and reported that the senior population would more than double over the upcoming 20 years, with Alaska having the fastest growing senior population. She projected that the senior population would level off around 2032, at which time there would be a spike for people aged 85 and older.

MS. DANIELLO addressed slide 8, "Rates of Alzheimer's Increase with Age," which showed that people over 85 years of age often had mixed dementia, and that women were more at risk, as they lived longer than men. She reported that women over 60 years of age were twice as likely to develop Alzheimer's disease as to develop breast cancer.

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MS. DANIELLO, in response to Representative Wool, clarified that half of the people with Alzheimer's disease and related dementia were in that age bracket [85 years and older].

REPRESENTATIVE WOOL asked if it was possible to differentiate among the various dementias.

MS. DANIELLO replied that each of the nine types of dementia had its own defining characteristics. She relayed that there were other risk factors for developing dementia, including cardio

vascular issues, diabetes, and head injury. She said that there had been an increase in these conditions due to an increase in the senior population, as well as a corresponding significant increase in survival.

MS. DANIELLO clarified that there were nine different types of dementia.

REPRESENTATIVE WOOL asked about the remaining 37 percent of the population on slide 8.

CHAIR SEATON asked for clarification that the percentages on slide 8 were for 46 percent of those over 85 years of age had dementia, or that 46 percent of all dementias over 85 years of age were Alzheimer's disease.

MS. DANIELLO expressed agreement that the slide projected the rates for prevalence of Alzheimer's disease in each age group.

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MS. DANIELLO moved on to slide 9, "Alaska Alzheimer's Disease Prevalence, Ages 65+, 2014 - 2025" which reflected the number of people in Alaska over 65 years of age with Alzheimer's disease. She noted that currently there were 6,100 people, which would almost double to an estimated 11,000 in the next ten years, an 8 percent annual increase. She noted that this did not include related dementia, or early onset Alzheimer's which affected people 30 - 64 years of age. She estimated that 8,000 Alaskans had Alzheimer's disease and related dementias.

REPRESENTATIVE STUTES asked if the doubling of Alzheimer's in the upcoming ten years was related to the aging population.

MS. DANIELLO expressed agreement that the aging of the population greatly contributed, and, in addition, there was a relationship with head injuries, diabetes, depression, and chronic health conditions. She observed that this was a conservative estimate for Alzheimer's disease and related dementias. She opined that, as Alaska had the fastest growing senior population 65 years of age and older, it could be a leading state for a population of older people with Alzheimer's disease and related dementias. She noted that, in Alaska, about one third of those with Alzheimer's disease and related dementias lived by themselves.

MS. DANIELLO presented the chart on slide 10, which reflected the death rates in Alaska over the past ten years. She relayed that there had been an increase in the mortality rate for Alzheimer's disease, basically due to the increase in the senior population, although there was a decrease in mortality related to cancer, heart disease, and stroke.

REPRESENTATIVE TARR asked about the actual health problems attributed as the cause of death, in conjunction with Alzheimer's.

MS. DANIELLO said that the cause of death could be related to a variety of health problems, although it was most often attributed to pneumonia.

MS. DANIELLO shared slides 11 and 12, "Needs Assessment: Family Caregiver Community Forums," which had been held in seven locations across the state, with 161 people in attendance. She reported that a lot had been learned from the participants, especially that there was a general lack of public awareness and a misunderstanding about Alzheimer's disease that often lead to stigma, embarrassment and denial for the condition. Although there was not a treatment or a cure, services did help. There were reports from the family caregivers about inadequate services, especially in the rural areas, as well as declared needs for specialized services. She stated that people with cognitive impairment often had functional limitations and often needed family care givers, although the care givers had shared that it was stressful, as they lacked the training. She spoke about the need for safe and appropriate housing, especially for assisted living homes. She reminded the committee that the Pioneer Homes had very long wait lists, and that there were not very many licensed facility options for dementia and other challenging behaviors. She mentioned the concerns of safety for those with Alzheimer's disease who had a tendency to wander into life threatening situations.

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MS. DANIELLO moved on to slides 13 and 14, "Needs Assessment: Family Caregiver Survey," and reported that mostly women responded to the survey, half had college educations, and 70 percent were in a long term relationship. She noted that they were "well-seasoned care givers" and had each provided care for about four years. The respondents said that the most difficult challenge for them was stress, which often lead to depression, which Ms. Daniello said was consistent with the national

findings. She reported that almost one-third of the care giver respondents said that Adult Day Care was the most important support service, followed by transportation, support groups, personal care assistants, and respite.

MS. DANIELLO explained slides 15 and 16, "Needs Assessment: Behavior Risk Factor Surveillance Survey (BRFSS) & Perceived Cognitive Impairment," a graph which showed that at later ages, beyond 70 years of age, the percentage of the population with perceived cognitive impairment increased. The definition for perceived cognitive impairment was memory loss progressively getting worse. She said that it helped to better understand the relationship between memory loss and how it affected people's daily lives. She noted that, across all age groups, about 9 percent had perceived cognitive impairment, which included brain injury. She reported that people with perceived cognitive impairment had an increased likelihood for smoking, depression, and cardio vascular health issues.

MS. DANIELLO moved on to slide 17, "Perceived Cognitive Impairment & Daily Life," and emphasized that it did affect people's daily lives and their ability to work, engage in social activities, and perform household chores, and it also increased their mental distress.

MS. DANIELLO directed attention to slide 18, "Alzheimer's Disease & Related Dementia Prevalence within the State's Long Term Services & Supports." She stated that the most prevalent services used included the Pioneer Homes, Adult Day services, and the National Family Caregiver grant program administered by the Division of Senior and Disabilities Services which provided respite for family caregivers.

REPRESENTATIVE TARR asked about the actual amount of unmet need beyond the facilities that offered these services.

MS. DANIELLO replied that this was a current unknown and she opined that it would be reviewed in the future. She offered her belief that the Adult Day Care had served 416 seniors statewide during the last fiscal year, of which 66 percent had Alzheimer's disease and related dementia.

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REPRESENTATIVE VAZQUEZ asked about the number in Anchorage [of Adult Day care centers].

MS. DANIELLO said that she would return with that information.

REPRESENTATIVE VAZQUEZ asked about the number of participants and the extent of the waiting list for those centers.

REPRESENTATIVE TARR, noting that there was currently an unmet need, asked how was it possible for providers and programs to transition to get ahead as the projection was for an even greater need in the near future.

MS. DANIELLO expressed her agreement. She reported that nationally, people with Alzheimer's disease and related dementia were about 18 times more at risk for being in a nursing home. She pointed out that the more people could be served with less costly care, for example, the home and community based services, the longer the state services could serve people, slide 19, "State Program Average Annual Cost per Recipient." She noted that the graph showed the average costs for each service, which included the senior grant programs that supplied these essential core services, Medicaid personal care assistance and Medicaid waivers, Pioneer Homes, and skilled nursing care.

MS. DANIELLO moved on to slide 20, "Alaska's Roadmap to Address Alzheimer's Disease and Related Dementia (ADRD)" and declared that this was important because it was the first ever statewide planning process to address the needs of people with Alzheimer's disease and related dementia. She declared this to be a growing population of vulnerable people that would increase the cost of care in Alaska. She stated that, as there was not any cure, the aim was to increase public awareness, to understand the current impact in Alaska, and to have a set of goals, recommendations, and performance measures to address this condition in a comprehensive way.

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NANCY BURKE, Senior Program Officer, Alaska Mental Health Trust Authority, Department of Revenue, referred to the six goals on slide 21, "Roadmap Goals," which had been compiled by the aforementioned stakeholders from the many options. She listed these to include public awareness for prevention and promotion for a healthier lifestyle through diet, exercise, and attention to sleep. She spoke about research for northern climates and the use of Vitamin D. She listed the remaining goals: to improve access to affordable housing, services, and supports for individuals with ADRD at all stages of the disease and to provide in-home supports to lower the cost to the state; to

optimize the quality, safety, and efficiency of services to people with ADRD, and to develop more specific technical care; to develop a long term care workforce trained in dementia care; to improve quality of life for family and other informal caregivers; and to increase monitoring and research into ADRD prevalence, cost of care, prevention, and treatment.

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MS. BURKE addressed slide 22, "Seven Prioritized Strategies," and directed attention to the fact that the partnership had resulted in each department taking the lead for a priority, including the Alaska Mental Health Trust Authority assisting plans through state Medicaid plan services, the Long Term Care Ombudsman looking at improved regulations for assisted living homes and other residential settings, and AARP reviewing training to caregivers to reduce stress.

MS. BURKE reviewed slide 23, "Goal 2.1.1 Medicaid Reform: 1915(i) and 1915(k) Options." She said that this was an example of how the Alaska Mental Health Trust Authority was helping the boards. She pointed out that currently there were projects looking at ways to better use the 1915(i) or 1915(k) options. She noted that a significant aspect to these options was that it allowed them to bring the services closer to the in-home support services. She reported that the existing waiver programs were not able to serve individuals with Alzheimer's disease or related dementia until they were physically unable to take care of themselves. She stated that both the 1915(i) and 1915(k) options moved it closer to the home, and allowed services to be received before the disease impacted their physical abilities. It also provided access to greater federal match, while bringing us closer to compliance with some of the federal requirements regarding conflict-free case management and the rules determining where services needed to be provided.

MS. BURKE introduced slide 24 "Next Steps," and explained that the Roadmap was viewed as a living document, and that each of the partners facilitating these strategies would meet regularly to move it forward. She said that this was a critical time, as things were changing in the system, and there could be effective changes to the services for those with Alzheimer's disease.

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CHAIR SEATON referenced the first of the seven prioritized strategies [slide 22], "educate Alaskans about prevention," and

stated that the House Health and Social Services Standing Committee had worked on looking at causes and prevention. He said that the message from the commission seemed to be that there were no cures or preventions [for ADRD], but that stress was related to Alzheimer's disease. He pointed out that the committee had submitted recent articles that Vitamin D could lower this risk by half, as well as lowering the speed of its development by half. He referenced other studies about the reabsorption of beta amyloid plaques with treatment of Vitamin D and a systematic review that showed a higher proportion of people with lower Vitamin D levels developed ADRD. He questioned why there was nothing in the presentation regarding these prevention means. He asked to review the scientifically based studies for stress being a cause of ADRD. He wondered about the mechanisms for choosing what to attribute to ADRD, while other scientific based studies were not included.

MS. DANIELLO replied that the commission had previously conducted a "healthy body, healthy brain campaign" which had focused on the importance of a healthy lifestyle to reduce risk for ADRD, as well as for brain health. She stated that there was a lot of research on the benefits of a healthy lifestyle with good nutrition, exercise, and regular mental engagement, and she offered her belief that it was necessary to encourage regular visits to the doctor, have bloodwork done, and have the proper nutrients, including Vitamin D. She stated that it was important to look at holistic health.

MS. BURKE acknowledged that Chair Seaton offered a fair critique, reporting that Alaska Mental Health Trust was looking at more ways to work in prevention. She shared that there was currently more focus on who was already in the system, and that there should be more attention paid to the science and the research available to help with prevention.

CHAIR SEATON expressed his concern that this presentation was speaking in broad sweeping generalities for being healthy, even though there were scientific studies showing direct relationships which were being ignored. He declared that the wrong message was being sent, as the statement to have a healthy lifestyle was too broad and was not creating any action. He encouraged the commission and the Alaska Mental Health Trust to support justifiable scientific options that were also cheap. He referenced the aforementioned studies that lowered the risk for ADRD. He expressed his support for prevention of ADRD.

HB 76-GOV COUNCIL ON DISABILITIES/SPECIAL ED

3:53:55 PM

CHAIR SEATON announced that the next order of business would be HOUSE BILL NO. 76, "An Act relating to the Governor's Council on Disabilities and Special Education."

3:54:31 PM

GRACE ABBOTT, Staff, Representative Charisse Millett, Alaska State Legislature, explained that proposed HB 76 removed the word "gifted" from the enabling statute for the Governor's Council on Disabilities and Special Education. She paraphrased from the sponsor statement, which read:

The mission of the Governor's Council on Disabilities and Special Education is to, "[create] change that improves the lives of Alaskans with disabilities." Since 1978, the Council has provided a constructive process that has connected the public with policymakers to ensure the thoughtful development of an efficient and seamless service delivery system that meets the needs of individuals with disabilities across their life spans.

However, within their enabling statutes, the State of Alaska also included "gifted" persons among the individuals that the Council need work for and support. The Council believes the term "gifted" to be confusing and ill-fitting within the scope of their aims and objectives. Furthermore, they believe "gifted" should be removed for the following reasons:

Exceptionality is not a disability that entitles students to special education. Gifted education is a regular education program over which the council has no oversight.

Gifted children are not eligible for additional services under the Individuals with Disabilities Education Act (IDEA) or the Americans with Disabilities Act (ADA), policies whose adherence is required per the Council's responsibilities.

Neither federal nor state law provide for special employment benefits, or special avenues through which

to advocate for employment for those classified as gifted.

The Governor's Council works tirelessly to advocate for and access housing, employment, independent living, health, transportation and community inclusion for Alaskans with disabilities. Removing the word "gifted" from their enabling statutes allows Alaska law to be updated with the most accurate representation of the mission and work of the Council, as well as provide future Council membership with a clear roadmap for success.

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CHAIR SEATON asked for clarification, page 2, line 14, that changing the citation was updating the reference in the federal registry.

MS. ABBOTT expressed her agreement, noting that the policy was the same at the federal level.

[3:57:11 PM](#)

[Chair Seaton opened public testimony]

PATRICK REINHART, Executive Director, Governor's Council on Disabilities and Special Education, reiterated that the proposed bill was "cleaning up our mission versus what's in our statute, so that we don't get confusion on the public." He stated that this had been on the agenda to fix for quite a while.

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CHRISTIE REINHARDT, Governor's Council on Disabilities and Special Education, said that she was staff for the council, specifically for the Special Education Advisory Panel. She reported that one council responsibility was to the Individuals with Disabilities Education Act (IDEA) stakeholder group, which oversees and advises special education. She pointed out that the Special Education Advisory Panel was federally mandated, although Alaska was the only state where this panel resided with the Council on Developmental Disabilities. She said that the panel advised and administered special education programs statewide. She pointed to a conflict, noting that in 2002 there had been regulatory changes made to state education regulations in response to statutory changes which had removed gifted and

talented education from special education and related services. She reported that gifted and talented exceptionality was no longer considered a disability program. There were now two entirely separate programs. One of which, the special education program, had very complicated, mandated federal and state statutes, regulations, policies, and procedures; whereas, the gifted and talented program was primarily developed and administered by the local school district or education agency. She noted that these programs were also funded differently. While there were some individuals with a disability who were also gifted and talented, there was very little overlap between the two programs. She pointed out that, as there was very little state oversight for the gifted and talented program, there was often confusion from the parents with concerns for the quality of the school districts' gifted and talented education programs. She said there was not a gifted and talented education program advisory committee and no specified mandated funding. She expressed an understanding for the concerns of the parents for their children's education, but this did not fall within the purview of the council to effectively advise, monitor, or advocate.

CHAIR SEATON asked about whether it was an efficient process for the Governor's Council on Disabilities and Special Education to be the funding conduit.

MS. REINHARDT replied that this was a fantastic partnership, as they were able to work closely with the early intervention program, as well as some of the other programs at the council which looked across the life span of support for individuals with a disability. She pointed out that the kids in school would be transitioning into the workforce, and as Alaska was small enough, the program work could be through one centralized agency. She noted that the Special Education Advisory Panel met once each month, even though it was only federally required to meet quarterly, and that the panel was a very active working group with a large number of committed individuals invested in quality special education services in Alaska.

REPRESENTATIVE WOOL asked if one of the purposes for the change to remove gifted was to relieve responsibility by the council to the parents of gifted children.

MS. REINHARDT replied that a requirement for gifted and talented programs was for the local education agency to have a review plan, which was administered by the local school board, as opposed to being overseen by the state. She reported that the

council worked at a state policy level, and not at the local level. She shared another difference that special education funding was federal and state match, whereas there was not any designated funding for gifted and talented education. She stated that local school districts were able to access gifted and talented funding through the AS 5(d)(6) funds. She declared that the spending was determined at the local level.

REPRESENTATIVE VAZQUEZ asked for the total budget for the council.

MR. REINHART replied that the council budget was a bit less than \$2.1 million, and its responsibility to the special education advisory panel was a pass through amount from the federal government to the Alaska Department of Education and Early Development. He offered his belief that this amount was about \$170,000. He explained that the council was multi-level, combining many different responsibilities, including the special education advisory panel.

REPRESENTATIVE VAZQUEZ asked how much of the budget was from general funds.

MR. REINHART stated that there were not any general funds among the ten funding sources in the council budget, which included Alaska Mental Health Trust Authority funding and pass through funding from the federal government.

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CHAIR SEATON closed public testimony.

[HB 76 was held over.]

[4:08:11 PM](#)

ADJOURNMENT

There being no further business before the committee, the House Health and Social Services Standing Committee meeting was adjourned at 4:08 p.m.